Iowa Autism Council

October 6, 2010 meeting notes taken by Sue Baker and Beth Buehler, sub for Sonia Lewis.

Absent is Dr. Jeanne Prickett, Keith Gatrost, Katherine Byers, Dr. Charles Wadle, Jim Mumford, Toni Merfeld, and Sonia Lewis.

Present: Josh Cobbs, Danielle Sharpe, Steve Muller, Dr. Debra Waldron, Casey Westoff, Kenda Jochimsen, Karn Johansen, Susan Smith, Barb Stineman, Becky Harker, Pamela Parker, Dr. Linda Louko, Sue Baker, Dr. Marty Ikeda, Frank Forcucci, and Beth Buehler-Sapp.

DE SURVEY: Marty Ikeda started by talking to the group about the survey which the Bureau of Student and Family Support Services has been developing to use to identify who the kids are and what services they need to support the goal of the "Eliminating the Achievement Gap by 2020". The department member's working primarily on this are Sue Baker, Frank Forcucci, Toni Merfeld, and Sean Casey. The study from the IAC is to define who the students are to match w/ educational achievement and what services are the students getting.

In speaking with Special Education Directors regarding data collection, students identified in their sampling process for gathering data would be those already identified as receiving special education services. Concerns ensuring that students in the sample are students on the spectrum and what checks are there to assure they fall within the spectrum. We do not want to be making too many inferences from the data. Directors seem supportive of council work.

AEA Chief Administrators are asking Special Education Directors to make sure everyone throughout the AEA's statewide have what they need to serve students.

Question was asked by Deb: Is there any plan to link these Iowa Autism Council survey results to any other information sources ie the DHS survey? Josh says we think this (linkage) is going on, so our (IAC) task work is to find out what is going on for parents and professionals.

DHS SURVEY: Danielle Sharpe asked about the DHS survey and Josh said he thinks this has kind of stalled out. Dr. Deb Waldron responded that before winter she hopes to get some movement on that.

GENERAL AND SPECIAL EDUCATION SUBCOMMITTEE SURVEY

RECOMMENDATIONS: Josh read the Education Executive Summary and Immediate Recommendations to the group which the group has created and pending review and approval by the council these are what will be submitted to the governor's office. Possible Timeline: January 15th, 2011 the questions will be complete. Participants complete the survey by March 1, 2011. May 15th we will have data back. June 15th will be presentable data and then the additional questions to be developed after that.

DISCUSSION: Kenda Jochimsen asked if the survey questions will only be related to education.

There are questions that could be asked which might overlap but would be used in relation to providing services needed in order to get education services. (i.e., medical needs for ambulation, etc.)

DISCUSSION: Voucher to private facilities.

Steve: stated that in relation to #5 under the immediate recommendations, this may allow use of a voucher rather than to create a voucher based system. Is this group asking for voucher system as a position which is a discussion question for today? Josh's goal is to create a voucher system. A voucher system may not make the list of recommendations, so we need to discuss it.

Dr. Linda Louko asked how this is related to what Marty just spoke about?

Recommendation #5 is "Increase the regulatory oversight of Home and Community Based Services (HCBS) to include observing the quality of interactions between the service provider and the recipient of services.

Open Enrollment was mentioned and Marty stated that with regard to open enrollment, the IEP team of a district is supposed to find an appropriate program to serve the student.

Becky Harker asked that this be looked at in relation to what's already available. Becky: would want survey data to verify the voucher recommendation.

Josh: Many states have gone to voucher status for those who cannot meet his needs, we should be able to sent a child to another location to meet his needs. Parents should have options to relocate those funds. It may a large school environment versus a small er school environment that is needed.

A question is posed: open enrollment exists, but if the school does not have appropriate services the IEP team has the responsibility to find the school. Should the language be changed since it exists, or is the wording not to infer a solution? Becky suggested an example: Local school can contest they are providing an appropriate program with the parent says not so, the funding does not follow a kid. This is a slippery slope (money not follow an individual). Josh says how much does it take to educate an individual? The IAC needs to know so we can we ball park services.

Conflict still exists with number 5 (voucher), but perhaps the option would be different or the array of options could be different. Should we investigate the portability to create information to draft into a workable solution? Josh: choice and menu of choices is what parents want. By law they may have an appropriate program, but a clinic program exists to serve him quicker, they should have access to that. It may be a better fit. He stated that from a "business" standpoint an entity looks at "how much does it take to serve X", in reality the \$ doesn't necessarily follow the kids directly.

Linda Louko said that conflict would still exist but that there would be another choice. If we have consistent services, #5 (voucher) would not be needed.

Josh stated, "We really need to investigate how we're educating the kids."

Marty expressed his concern that it's a solution that's not yet tied to the data and needs to be studied.

Becky Harker stated that parents of students with disabilities have concerns.

Josh observed that "Teachers may be struggling to connect to all these different kids at various levels. He believes that when survey results are back that gaps will be visualized.

ACTION: Council members agreed to remove recommendation #5 for now pending more research.

DISCUSSION CONTINUED: Becky Harker asked about the variety of formats (print, e-mail, survey monkey, alternate languages, etc.) that the survey would be available in.

Marty interjected that the Department of Education was contracted with an entity named "Transact" to identify the 6 most frequently used languages.

Dr. Debra Waldron asked "Who would actually be conducting the survey process?"

Marty stated that the Department of Education would administer the survey on behalf of the council.

Dr. Waldron expressed concern that even though the survey is in aggregate form that she recommends it be submitted to an Institutional Review Board prior to its implementation.

Dr. Linda Louko stated that the U of I has an Internal Review Board as do the other two state universities and some private institutions such as Drake University for example. Their objective is to protect confidentiality and often the identity of the subjects participating in the survey.

Dr. Waldron commented that they review "How you're going to conduct a survey", re: "Recruitment Methods", "Malfeasance" (Definition-Being legally unjustified, harmful, or contrary to law,) are there some benefit to those who are participating? She related that this is often helpful in regard to documents, particularly if you're attempting to get something published. She said the time for an IRB process varies depending on who you contract with for IRB services and their workload.

Marty Ikeda commented that it's hard to get IRB's to review and approve proposals that are not authored/produced by them (their institution).

Becky Harker asked "How might some parents be restricted?" This is meant in regards to language skills such as a different language or language level (i.e. 12th grade reading) being prohibitive. The reading level is pretty sophisticated and you don't have parents reading at this level in both the letter and survey questions, was her input.

Josh said that yes, there would be some basic terminology such as for example, IEP's that a person would need to understand.

Becky Harker stated that this is really wordy to a person who does not read well, i.e., reads at a lower reading level. An accommodation for this might be to offer multiple choice answers to rather than to require a written-out answer.

Josh commented that as we add more layers, progress halts; we would want a timely IRB process.

Marty posed this question to the council, "Is there a way to know what percent we have to determine that everyone who needs to is being served?"

Josh stated that "Across the state, at age 13, there's a deficit/hiccup in services available.

Kenda Jochimsen indicated that surveys have been done through an education professional at the collegiate level to review the content.

Josh reminded folks to be careful about what you tell parents and keeping your promises.

Dr. Waldron asked, could we recommend DE undertake the survey and make sure it is conducted, does no harm, and provide the data to the IAC? Recommend the task to another entity to conduct the survey is another option. DE is the reasonable entity, but inquire about protecting the survey re: informed consent. If outside entity is chosen, they can do it but will not do it without funding. DE is providing support through internal funding, so the council could recommend that the Department of Education administer the survey.

Marty: As a Dept we don't have enough sense of who the population is and stated that once kids are identified, IEP's can be looked at to determine what services students are receiving.

Marty expressed the concern that we also need to make sure that parents understand that they can't use data determined during the survey process to dictate service determinations by IEP Teams. This has happened with other surveys.

Josh acknowledged that we haven't gotten every mechanism completed. Somehow, someway, we need to find out who these parents are so we can help gather information.

Marty stated that we need the right information to answer important questions.

Josh is anticipating finalization of the survey in November 2010.

Dr. Waldron stated "We want it to be a pretty good survey that helps families in the way needed and observes safeguards." She feels it will take 2-3 months necessary for professional review.

Josh asked that all council members please review the surveys and give feedback. Analysis should be spelled out up front. Should we stay with questions (integrity) and not use for personal gain? We need to make sure parents understand that data obtained from survey are not an in-road for parents to initiate litigation.

Too many questions are currently on the survey, says Becky.

Josh asked the question that if a district/AEA says they're providing 3 hours of speech per week and are not seeing that student than how are they doing this?

Dr. Louko suggested the comparison of answers for the questions: What services are needed and what services are being provided?

Becky Harker felt a question for parents should be, "Do you feel like you know enough to advocate for your child?

Danielle Sharpe mentioned that for IEP students receiving services, parents don't get regular verifications (weekly) informing them what services their children are receiving.

Becky Harker agreed with Danielle; she suggested that most likely, in comparison to most parents, Danielle understands a lot of the situation and is very involved, where that is not the situation for the majority of parents.

Josh stated that it's helpful that Marty and Department of Education staff are willing to help the council drive the data. Data will be general and not relative to a specific student.

Marty stated "We can't compel service providers to make changes based on the research data captured within this survey process."

Kenda stated that the survey should be something used to gather data regarding categories rather than something to pick up and use.

Marty <u>summarized</u> that important factors are: How is the sample drawn, Confidence of sample, and would a participant be willing to participant again.

Josh stated that the common fears are that repeat surveys will ask the same questions and protect the same populations.

Steve Muller asked the questions, "Do parents know what they can get?" and "Do parents know what their children need?"

Parents are unaware of services that could be provided to eligible individuals.

Kenda commented that parents understand LRE but by whose definition? (This would vary based on student's condition) Would a glossary be needed within the survey?

Dr. Louko voiced that she would rather see this move forward rather than be held up longer.

Josh also stated we need to get this survey rolling, wordsmithing the final questions, inquire about IRB approval, etc. If Deb and Kenda would be willing to join the sub-committee for the survey this would be very helpful.

REQUESTED ACTION FROM MEMBERS: Josh informed the council that the next meeting is November 17^{th} and asked everyone to review the survey and get your feedback to the sub-committee by November 3^{rd} . Indicate whether you're referencing the parent survey or the professional survey.

PARENT, GRANDPARENT AND SIBLING TRAINING NEEDS SUBCOMMITTEE RECOMMENDATIONS: Dr. Linda Louko reviewed the October 2010 Draft of Findings with the council. The three recommendations were shared.

DISCUSSION: Family to Family Iowa is in year 2 of 3.

Susan Smith stated that I-PART can provide on-site behavioral consultations to individuals with autism. Other behavioral disorders such as ODD, etc. can use I-PART also.

Dr. Waldron stated that specific services should be listed within the training resources that are currently listed.

Josh – Who gets on an Autism Resource Team? An Autism Resource Team is made up of mostly AEA and very few district staff. These are the teams that can support the IEP teams and create the appropriate IEP's for students. He questions the recommendation of expanding the numbers of members on the Autism Teams.

Marty – If Autism Resource Teams can't do what they need to do now, then is adding to their list of numbers a good idea?

Becky Harker posed the question, "What knowledge, skills, and attitudes do parents need to be an effective advocate for their child? Should that be addressed?

AEA Special Education Directors suspect that there is a disconnect between the best practices which were written 15 years ago.

It was suggested that we're OK with bullet #2 (feedback from SPED Directors and how data can be collected) but need to look further at bullet #1 about increasing the number of members on the team particularly.

Marty: He disagrees that you need to be an expert in ASD, so we need to know skills of teacher providing services, and know when we don't need an ART in there supporting the

teacher. What do we think the minimum skills are that they need, where are they needed, and how to we increase capacity of school to learn.

Dr. Louko asked the question regarding parent training, "Should we provide parents with what they need rather than telling them where to find it?

Josh spoke to the fact that parents need to know what their child may and may not be eligible for. Examples were provided about various organizations having waiver service specialists or targeted case managers or county case managers that parents should be told about. Magellan Mental Health is hoping to provide parent support services in home to families.

Dr. Louko asked this question "Many physicians might be making a diagnosis and working with families but how do we find out who these folks are to serve/inform/train them?"

Dr. Waldron said that it should be embedded into the system. What do families really want?

Dr. Waldron offered to help define mental health facilities more broadly and this could replace the language under bullet #2 under medical facilities.

Karn Johansen said in support of in home training: "Lots of students are showing that inhome health training and information are very beneficial."

Dr Louko thinks this is due to the fact that program accessibility is becoming more known (for example Family to Family Iowa and Family 360 for kids with developmental disabilities / serious health problems.)

Becky Harker stated that focusing on function does eliminate some of the services available.

Josh suggested that a bullet be added to address peer training / self advocacy training

Sue Baker wondered if this falls within parent, grandparent, and sibling training recommendations but instead should be another sub-committee's work whose task is to look at child advocacy services.

Josh mentioned this could be applicable to children as well as adults: "Sometimes we forget that sometimes it's a chronological adult i.e., 26 years old who may need advocacy training."

Becky Harker mentioned that all groups; parents, children, siblings need advocacy training and that there should be a goal to pursue, implement and initiate this but what entity would do this?

Josh agreed to review what subcommittee (what letter's of IAC law things fall under.)

ADULT SERVICES SUBCOMMITTEE RECOMMENDATIONS: Numbers 1 and 2 were from last year's recommendations. Steve Muller began with an explanation regarding that state law prohibits spending more than the CAP in place allowed to spend on eligible services. The state is being forced by Medicaid to change the fact that counties can operate with waiting lists in some counties and not in others i.e. You shouldn't be able to get better services in one county than in another. This will go into effect on Jan 1, 2011 which is a 6 month extension of the original deadline.

DISCUSSION: Steve stated "It's important to keep folks active & engaged because these issues are lifelong."

Kenda: The Des Moines Chamber agency mentioned it would be willing to have some discussions and highlight those businesses that are doing this well working with our population. Kenda seen success with customized training. The question was posed: "What will we use to sell employers to get them to have more opportunities for ASD individuals?

Becky stated that sometimes employers have a hard time finding people to fill positions.

Kenda stated that this is a population that can be gainfully employed in the long term, so keep a long term focus in mind.

Becky mentioned that often times these folks get involved in job shadowing programs.

Marty mentioned Project Search, which provides stronger recommendations to expand opportunities for kids. Often the hurdles are related to where opportunities are versus where residency is.

Becky stated that there is a disconnect between the perception and the specific skills.

Becky asked in regards to writing something for the governor and the legislature, "What can this council do?"

Kenda posed the question "Couldn't we get some school district folks in to listen and ask them what barrier's they encounter during transitioning?"

ACTION: Josh suggested that the sub-committees could look at inviting the pertinent guests in for these conversations on an agenda at an upcoming meeting.

DISCUSSION CONTINUED: Steve Muller observed that it's such varied population i.e.; candidates vary as follows:

Lots of skill – Little need (these are the ones highly placed)

Lots of need – Little skill

A job fair to nourish these factors would probably be very beneficial.

Steve talked about the 2 different scenarios: RCF (residential care facility) versus ICF (intermediate care facility) to help understand the background on one of the recommendations. An ICF-MR is usually more challenging to establish in a community due to

resistance by residents who hold a less than favorable view of how this facility in their community may create problems, particularly with the public's perception. ICF-MR are the only logical fit for some individuals based on their needs and are often a better fit for a large number of individuals in order to facilitate their safety and well-being. Sometimes RCF's which have far less supervision, sometimes have individuals placed in them who, in reality, should more likely be placed in an ICF-MR.

While costs may be higher for ICF-MRs and communities are often more comfortable with RCF's, safety for the challenged individuals should be the primary factor for determination of placement.

In the last 15 years no new ICF-MR's have been built as the ideological preference has been more towards RCF's but in many cases this may not be the safest placement.

Casey Westoff stated that advocates have worked hard to get waiver services available so that individuals can live in the type of environment that is best for them based on their abilities.

Steve related to the council that in the 80's the sate of Iowa made a contractual agreement with Iowa State University to provide trainers/surveyors to oversee facilities and meeting needs with regard to RCF's. Based on his knowledge of follow-through with this, it appears that somewhere services have fallen through the cracks.

As an example at Homestead which is an ICF-MR residents get medications, food, clothes, furniture, transportation provided with a daily cap of \$315 per individual. In contrast, HCBS (Home & Community Based Services) get services from multiple entities that add up to lots more than \$315 per day.

ONE MEMBER SUMMARY: Steve would like to see the ICF-MR funding cap removed in order to provide more equity and better quality of services to all eligible individuals.

Susan Smith observed that until there are places for folks to go, larger facilities can't close if there's no location to place these individuals.

In contrast, Steve says that currently there are over 60 kids in out-of-state placement and over 200 individuals total in out of state placement for these types of services.

SUMMARY TO SUBCOMMITTEE MEMBERS: No decisions made today. Josh recommended that council members write their new recommendations and bring them back to the council to vote on at our next meeting.

CHSC GRANT OPPORTUNITY: Deb Waldron: described a potential grant opportunity. CHSC was not successful for grant we applied for in June. Here is a new opportunity: Maternal Child Health organizations have small funding, \$15,000 for 10 states, not to fund personnel, but collaboration on some of the recommendations of a state plan Learn the Signs Act Early. This funding will be used to reconvene to work on recommendations the Iowa

Autism Council made: through the Early Identification subcommittee. We will be writing a grant for one year of funding to further IAC recommendations.

ACTION: She is asking for letter of support to reconvene the team and forward the early identification recommendations. We want a new mechanism in place to address content of these recommendations. Further information will be sent out to the full council and a request (by vote) to support this grant will be initiated by Josh.. If you want to be on this committee, let Deb know. The letter of support is needed by Oct 20th.

VIEWED THE COLLABORATIVE WEBSITE FROM OHIO: Sue will send the link: www.autism.ohio.gov to all members.

Josh: IAC could develop a similar collaborative website for Iowa. We could start to put the framework together for central information for resources that are available, services, and who to contact for services, trainings that are available. Ie: I just got diagnosed, where do I go? DE could provide resources with a subcommittee for development and implementation phase to get such a site at DE.

ACTION: Let's look developing a website motion was made by Casey seconded by Barb Vote: motion carried.

Josh motioned to adjourn the meeting, Linda Louko seconded.